

# The Lupus Fact Sheet



**AMERICAN COLLEGE  
OF RHEUMATOLOGY**  
EDUCATION • TREATMENT • RESEARCH



# Lupus

Systemic lupus erythematosus, referred to as SLE or lupus, is a chronic (long-term) disease that causes inflammation — pain and swelling. It is sometimes called the “great imitator,” because of people often confuse lupus with other health problems due to its wide range of symptoms.

In addition to affecting the skin and joints, it can affect other organs in the body such as the kidneys, the tissue lining the lungs (pleura) and heart (pericardium), and the brain. Most patients feel fatigue and have rashes, arthritis (painful and swollen joints) and fever.

Lupus flares vary from mild to serious. Most patients have times when the disease is active, followed by times when the disease is mostly quiet — referred to as a remission. Yet, there is much reason for hope. Improvements in treatment have greatly improved these patients’ quality of life and increased their lifespan.

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## Fast Facts

- Lupus occurs 10 times more often in women than in men.
  - Treatment depends on the symptoms and how serious they are.
  - Because it is a complex disease, lupus requires treatment by or consultation with a [rheumatologist](#), a doctor who is an expert in treating lupus and other rheumatic diseases.
  - People can live well with lupus if they actively work toward good health.
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## What causes lupus?

The immune system is the body’s defense system. When healthy, it protects the body by making antibodies (blood proteins) that attack foreign germs and cancers. With lupus, the immune system misfires. Instead of producing protective antibodies, an autoimmune disease begins and makes “autoantibodies,” which attack the patient’s own tissues. Doctors sometimes refer to this as a “loss of self-tolerance.”

As the attack goes on, other immune cells join the fight. This leads to inflammation and abnormal blood vessels ([vasculitis](#)). These antibodies then end up in cells in organs, where they damage those tissues. Why this inflammatory response begins is not clear. It most likely results from a mix of inherited tendencies and things in your environment. These include viruses, sunlight and drug allergies. People with lupus may also have an impaired process for clearing old and damaged cells from the body, which causes an abnormal immune response.

Most often, lupus starts in people in their 20s and 30s. The disease is more common in some ethnic groups, mainly blacks and Asians, and tends to be worse in these groups.

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## How is lupus diagnosed?

Lupus can be hard to detect because it is a complex disease that has many symptoms, and they can come on slowly. As experts in diagnosing and treating autoimmune diseases such as lupus, rheumatologists can best determine whether a patient has lupus and advise them about treatment options.

People with lupus often have symptoms that are not specific to lupus. These include fever, fatigue, weight loss, blood clots and hair loss in spots or around the hairline. They may also have heartburn, stomach pain, and poor circulation to the fingers and toes. Pregnant women can have miscarriages.

The American College of Rheumatology has a list of symptoms and other measures that doctors can use as a guide to decide if a patient with symptoms has lupus. If your doctor finds that you have at least four of these problems, and finds no other reason for them, you may have lupus:

- Rashes:
  - butterfly-shaped rash over the cheeks — referred to as malar rash
  - red rash with raised round or oval patches — known as discoid rash
  - rash on skin exposed to the sun
- Mouth sores: sores in the mouth or nose lasting from a few days to more than a month
- Arthritis: tenderness and swelling lasting for a few weeks in two or more joints
- Lung or heart inflammation: swelling of the tissue lining the lungs (referred to as pleurisy or pleuritis) or the heart (pericarditis), which can cause chest pain when breathing deeply
- Kidney problem: blood or protein in the urine, or tests that suggest poor kidney function
- Neurologic problem: seizures, strokes or psychosis (a mental health problem)
- Abnormal blood tests such as:
  - low blood cell counts: anemia, low white blood cells or low platelets
  - positive **antinuclear antibodies (ANA)** result: antibodies that can cause the body to begin attacking itself that are present in nearly all lupus patients
  - certain antibodies that show an immune system problem: anti-double-strand DNA (called anti-dsDNA), anti-Smith (referred to as anti-Sm) or antiphospholipid antibodies, or a false-positive blood test for syphilis (meaning you do not really have this infection)

If your doctor suspects you have lupus from your symptoms, you will need a series of blood tests to confirm that you do have the disease. The most important blood screening test measures ANA, but you can have ANA and not have lupus.

Therefore, if you have positive ANA, you may need more specific tests to prove the diagnosis. These blood tests include antibodies to anti-dsDNA and anti-Sm.

The presence of antiphospholipid antibodies can help doctors detect lupus. These antibodies signal a raised risk of certain complications such as miscarriage, difficulties with memory, or blood clots that may lead to stroke or lung injury. Doctors also may measure levels of certain complement proteins (a part of the immune system) in the blood, to help detect the disease and follow its progress.

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## How is lupus treated?

There is no cure for lupus, and treating lupus can be a challenge. However, treatment for lupus has improved a great deal. Treatment depends on the type of symptoms you have and how serious they are. Patients with muscle or joint pain, fatigue, rashes and other problems that are not dangerous can receive “conservative” treatment.

Common treatment options include:

- Nonsteroidal anti-inflammatory drugs (NSAIDs): **NSAIDs** decrease swelling, pain and fever. These drugs include ibuprofen (brand names Motrin, Advil) and naproxen (Naprosyn, Aleve). Some of these NSAIDs can cause serious side effects like stomach bleeding or kidney damage. Always check with your doctor before taking any medications that are over the counter (without a prescription) for your lupus.
- Antimalarial drugs: Patients with lupus also may receive an antimalarial medication such as **hydroxychloroquine** (Plaquenil). Though these drugs prevent and treat malaria, they also help relieve some lupus symptoms, such as fatigue, rashes, joint pain or mouth sores. They also may help prevent abnormal blood clotting.
- Corticosteroids and immune suppressants: Patients with serious or life-threatening problems such as kidney inflammation, lung or heart involvement, and central nervous system symptoms need more “aggressive” (stronger) treatment. This may include high-dose corticosteroids such as prednisone (Deltasone and others) and drugs that suppress the immune system. Immune suppressants include **azathioprine** (Imuran), **cyclophosphamide** (Cytoxan) and **cyclosporine** (Neoral, Sandimmune). Recently **mycophenolate mofetil** has been used to treat severe kidney disease in lupus – referred to as lupus nephritis.
- Biologics: Newer treatment options include drugs called biologics that are already approved for treatment of other rheumatic diseases such as rheumatoid arthritis. Examples are rituximab (Rituxan) and abatacept (Orencia).
- These two drugs are not approved for treatment of lupus. In 2011, though, the FDA approved a biologic, belimumab (Benlysta), for treatment of active SLE in adult patients, but not for those with severe disease. It is the first new drug approved for lupus since 1955.

This exciting treatment advance occurred thanks to research studies in patients—called **clinical trials**. It provides hope that some of the other drugs that researchers are testing in patients will help lupus. It also underscores the need for patients with lupus to take part in studies.

- **Combination treatment:** Health care providers may combine a few medications to control lupus and prevent tissue damage. Each treatment has risks and benefits. Most immune-suppressing medications, for instance, may cause major side effects. Side effects of these drugs may include a raised risk of infections as well as nausea, vomiting, hair loss, diarrhea, high blood pressure and osteoporosis (weak bones). Rheumatologists may lower the dose of a drug or stop a medicine because of side effects or when the disease goes into remission. As a result, it is important to receive careful and frequent health exams and lab tests to track your symptoms and change your treatment as needed.
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## Broader health impact of lupus

Even when it is not active, lupus may cause problems later. Some of these problems can be fatal. One of these problems is atherosclerosis (clogging of the arteries) that may develop in younger women or may be more severe than usual. This problem raises the risk of heart attacks, heart failure and strokes. Thus, it is vital that patients with lupus lower their other risk factors for heart disease, such as smoking, high blood pressure and high cholesterol. It is also important to have as active a lifestyle as possible.

Lupus may also cause kidney disease, which can advance to kidney failure and need dialysis. You can help prevent these serious problems by seeking treatment at the first signs of kidney disease. These signs include:

- High blood pressure
  - Swollen feet and hands
  - Puffiness around your eyes
  - Changes in urination (blood or foam in the urine, going to the bathroom more often at night, or pain or trouble urinating)
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## Living with lupus

Most people with lupus can live normal lives. Treatment of lupus has improved, and people with the disease are living longer. But, it is still a chronic disease that can limit activities. Quality of life can suffer because of symptoms like fatigue and joint pain. Furthermore, some people do not respond to some treatments. Also, you may not be able to predict when lupus will flare. Such problems can lead to depression, anger, loss of hope or loss of the will to keep fighting.

Here are a couple of tips that may help you when living with lupus:

- **Form a support system.** A good doctor-patient relationship and support from family and friends can help you cope with this chronic and often unpredictable illness.

- Get involved in your care. Learn as much as you can about lupus, your medications, and what kind of progress to expect. Take all your medications as your doctor prescribes, and visit your rheumatologist often to prevent serious problems. This lets your doctor keep track of your disease and change your treatment as needed. If you do not live near a rheumatologist, you may need to have your primary care doctor manage your lupus with the help of a rheumatologist.
- Stay active. Exercise helps keep joints flexible and may prevent heart disease and strokes. This does not mean overdoing it. Switch off doing light to moderate exercise with times of rest.
- Avoid excess sun exposure. Sunlight can cause a lupus rash to flare and may even trigger a serious flare of the disease itself. When outdoors on a sunny day, wear protective clothing (long sleeves, a big-brimmed hat) and use lots of sunscreen.

If you are a young woman with lupus and wish to have a baby, carefully plan your pregnancy. With your doctor's guidance, time your pregnancy for when your lupus activity is low. While pregnant, avoid medications that can harm your baby. These include cyclophosphamide, cyclosporine, and mycophenolate mofetil. If you must take any of these medicines, or your disease is very active, use birth control. For more information, see "[Pregnancy and Rheumatic Disease.](#)"

Rheumatologists have long been concerned that the female hormone estrogen or treatment with estrogen may cause or worsen lupus. Recent research showed that estrogen therapy can trigger some mild or moderate flares of lupus, but does not cause symptoms to get much worse. Yet, estrogen can raise the risk of blood clots. Thus, you should not take estrogen if your blood tests show antiphospholipid antibodies (meaning you already have a high risk of blood clots).

*Updated June 2015. Written by Ellen Ginzler, MD, and Jean Tayar, MD, and reviewed by the American College of Rheumatology Communications and Marketing Committee. This patient fact sheet is provided for general education only. Individuals should consult a qualified health care provider for professional medical advice, diagnosis and treatment of a medical or health condition.*

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